



May 28, 2013

Responses to Questions on the Record

Hearing of April 26, 2013, entitled:

“Does HIPAA Help or Hinder Patient Care and Public Safety”

Subcommittee on Oversight and Investigations, Committee on Energy & Commerce

Thank you again for the opportunity to testify at the hearing. I offer the following responses to questions for the record asked of me by Chairman Murphy and Representative Butterfield:

### **The Honorable Tim Murphy**

1. You have said that HIPAA has been “badly mangled.” What can be done to clarify the law? Do we need new legislative language? Do we need some clarification from the Office for Civil Rights? More public education? Please share with us your specific recommendations.

The HIPAA Privacy Rule provides an important set of “guardrails” with respect to how health care providers and health plans can access and disclose sensitive a patient’s identifiable health information. However, the Rule also recognizes that routine access and sharing of health data is critical to patient care and public health. Consequently, the Rule expressly permits the sharing of patient data – without constraints – for a number of important purposes, including treatment, for public health reporting, and for certain law enforcement purposes.

As I pointed out in both my written and oral testimony, the HIPAA Privacy Rule allows HIPAA covered entities (e.g., health care providers and health plans) to use or share information to avert a serious threat to health or safety.<sup>1</sup> In addition, the Rule also

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<sup>1</sup> Specifically, a covered entity may, “consistent with applicable law and standards of ethical conduct, use or disclose protected health information if [it], in good faith, believes the use or disclosure is necessary to prevent or lessen a serious and imminent threat to the health or safety of a person or the public; and [the use or disclosure] is to a person or persons reasonably able to prevent or lessen the threat, including the target of the threat.” 45 C.F.R. 512(j). Entities are expressly presumed to be acting in good faith if they are acting based on actual knowledge “or in reliance on a credible representation by a person with apparent knowledge or authority.” 45 C.F.R. 512(j)(4). On January 15, 2013, the HHS Office for Civil Rights issued a two-page, to-the-point letter to health care providers alerting them to this exception, in the hope of dispelling widespread myths that HIPAA does not permit such disclosures. <http://www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/righttoaccessmemo.pdf>.

allows covered entities to share a patient's information with someone who is involved in that patient's care or who is paying for that care – such as a family member, relative or close personal friend – unless the patient has objected to such sharing.<sup>2</sup>

However, we know from the testimony shared by family members at the hearing, and I know anecdotally from my own experience, both as a patient and as the Director of the Health Privacy Project, that covered entities too often interpret HIPAA to prohibit sharing of patient information, even in circumstances where the regulations clearly allow such sharing.

At the hearing, I used the term “badly mangled” to describe this over-interpretation of HIPAA.

The regulators (at the federal level, the Office for Civil Rights; at the state level, a state Attorney General) have no authority to penalize such over-interpretation, even though it frequently has real consequences for patients and their families. The Privacy Rule expressly allows entities to share patient information in these circumstances, but it does not require them to do so.

The HHS Office for Civil Rights has issued guidance on the provisions regarding sharing with family members, and that guidance is more clear and with less “legalese” than the regulatory text.<sup>3</sup> However, I do not think most providers or patients know this guidance exists. In addition, the guidance could be more comprehensive, and cover “frequently asked questions” and offer responses to specific factual scenarios, so entities have a more clear picture of what they can – and cannot – do under the law. At the hearing, Leon Rodriguez, the Director of the Office for Civil Rights, addressed a number of questions about an entity's ability to disclose information to family members in the event of a patient's “incapacity.” The details he offered were more comprehensive than anything that I have seen in previous guidance on that aspect of the Rule. Those details should be part of more comprehensive information about the Rule that is more easily accessible and broadly disseminated to the provider and patient community.

**I suggest that the Office for Civil Rights develop and more broadly disseminate guidance on both of these provisions. With respect to the provisions permitting disclosures to family members, the Office should work with provider and patient and family organizations both respect to developing the content of this guidance and in ensuring it is broadly disseminated.**

Here's another idea: The Office could establish a mechanism for gathering and affirmatively responding to complaints about over-interpretation of the HIPAA Privacy Rule. Such over-interpretations are not violations of HIPAA, but the Office could nevertheless be part of the solution through timely advice to entities of disclosures that are permitted. The Office also could routinely blog about such complaints –and the

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<sup>2</sup> 45 C.F.R. 510(b).

<sup>3</sup> [http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/provider\\_ffg.pdf](http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/provider_ffg.pdf).

proper interpretation of HIPAA in the circumstances in question – in a way that does not reveal the name of the entity in question as another mechanism for educating the public.

These suggestions do not require legislative action.

2. In your written statement you referenced a 2007 poll showing that 17 percent, or one in six adults, say they withhold information from their health providers due to worries about how the medical data may be disclosed. Are you aware of any studies that ask this question specifically with regard to the sharing of personal mental health information?

The statistic from my written statement is from general survey data, and you are correct that it does not focus on mental health information. We appreciate the additional time to find studies specifically addressing concerns about confidentiality and mental health information. Not surprisingly, general surveys of persons with mental health disorders are difficult to find (and we suspect confidentiality concerns among this population may be a reason why such surveys are so rare). Nevertheless, we were able to locate additional research on mental health and the need for confidentiality, and links to that additional research are attached to this response.

As further evidence of a widespread recognition of the need for confidentiality in mental health treatment, as of 2002 50 states (including the District of Columbia and excluding Arkansas) had specific statutes related to some aspect of mental health privacy.<sup>4</sup> Such privacy laws are not preempted by HIPAA if they provide stronger protections for mental health data.

### **The Honorable G.K. Butterfield**

1. Patients' rights to access psychotherapy notes are restricted more than other types of health records. Can you please explain what sort of access individuals have to that information? What happens if the patient believes the information to be inaccurate?

As I noted in my written statement, the Privacy Rule provides additional protections for psychotherapy notes. The term "psychotherapy notes" is defined as the personal notes

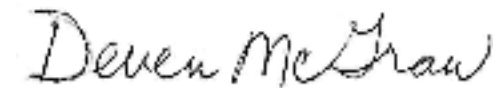
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<sup>4</sup> Beckerman, J et al., "Health Information Privacy, Patient Safety, and Health Care Quality: Issues and challenges in the Context of Treatment for Mental Health and Substance Abuse," BNA's Health Care Policy Report, vol. 16, No. 2 (January 14, 2008). This article includes a comprehensive discussion of HIPAA's provisions regarding "preemption."

of a mental health professional taken during a counseling or therapy session.<sup>5</sup> Entities covered by the Privacy Rule must obtain a specific, formal authorization from the patient in order to disclose psychotherapy notes in most circumstances (such notes can be used internally to treat the patient).<sup>6</sup>

The right of patients under the HIPAA Privacy Rule to access and obtain a copy of their health information does not apply to psychotherapy notes.<sup>7</sup> The Privacy Rule does provide patients with the right to request a correction to information in a provider's medical record; however, this right does not extend to information that the patient does not have the right to access.<sup>8</sup> As a result, it is unlikely that many patients would be provided with the ability to view their psychotherapy notes, and it would be solely in the discretion of the medical professional who created those notes (or the record holding institution) with respect to whether any correction would be made.

Respectfully submitted,

A handwritten signature in dark ink that reads "Deven McGraw". The signature is written in a cursive, flowing style.

Deven McGraw  
Director, Health Privacy Project

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<sup>5</sup> Psychotherapy notes are "notes recorded (in any medium) by a health care provider who is a mental health professional documenting or analyzing the contents of conversation during a private counseling session or a group, joint or family counseling session and that are separated from the rest of the individual's medical record. The term 'psychotherapy notes' excludes data relating to medication prescription and monitoring, counseling session starts and stop times, the modalities and frequencies of treatment furnished, results of clinical tests, and any summary of the following items: diagnosis, functional status, the treatment plan, symptoms, prognosis, and progress to date." 45 C.F.R. 164.501.

<sup>6</sup> 45 C.F.R. 164.508(a)(2). Such notes may be used by the originator in order to treat the patient; they also can be used for training purposes and to defend against a legal action or other proceeding. *Id.* Of note, the U.S. Supreme Court, in a case recognizing psychotherapist-patient privilege in federal rules of evidence, acknowledged the critical role that confidentiality of psychotherapy notes plays in mental health treatment: "Effective psychotherapy ... depends upon an atmosphere of confidence and trust in which the patient is willing to make a frank and complete disclosure of facts, emotions, memories, and fears. Because of the sensitive nature of the problems for which individuals consult psychotherapists, disclosure of confidential communications made during counseling sessions may cause embarrassment or disgrace. For this reason the mere possibility of disclosure may impede development of the confidential relationship necessary for successful treatment." *Jaffree v. Redmond*, 518 U.S. 1 (1996).

<sup>7</sup> 45 C.F.R. 164.524(a)(1)(i).

<sup>8</sup> 45 CFR 154.526(a)(2)(iii).

## **Privacy Implications With Respect to Mental Health Treatment**

### Confidentiality and Mental Health Treatment of Adolescents

A critical element in privacy is the confidentiality between a patient and the health care provider and even more critically, how perceptions of confidentiality affect willingness to seek care or disclose symptoms/thoughts with the mental health professional.

Professional societies promote confidentiality with adolescent patients, but have also recognized the importance of involving parents in serious healthcare events. Specifically, the Society for Adolescent Medicine has stated that, “confidential health care should be available, especially to encourage adolescents to seek healthcare for sensitive concerns ...”, and parental involvement should be encouraged, but not mandated.

([http://www.adolescenthealth.org/AM/Template.cfm?Section=Position\\_Papers&Template=/CM/ContentDisplay.cfm&ContentID=2597](http://www.adolescenthealth.org/AM/Template.cfm?Section=Position_Papers&Template=/CM/ContentDisplay.cfm&ContentID=2597))

Studies have found that adolescents are more willing to disclose highly personal information (including mental health information) to a physician after being given assurances of confidentiality.

(<http://jama.jamanetwork.com/article.aspx?articleid=418249>)

(<http://jama.jamanetwork.com/article.aspx?articleid=195185>)

Underlining the importance of confidentiality in adolescent healthcare, an anonymous survey of 1295 Massachusetts high school students found that 25% reported that they would be willing to forgo health care in some situations if their parents might find out.

(<http://jama.jamanetwork.com/article.aspx?articleid=404397>)

Other studies have found similar results:

(<http://www.ncbi.nlm.nih.gov/pubmed/10447039>)

(<http://www.ncbi.nlm.nih.gov/pubmed/12169074>)

Other works have shown that there are variances amongst health care providers willingness to discuss confidentiality with their adolescent patients or even to provide them with such confidentiality.

(<http://pediatrics.aappublications.org/content/111/2/394.short>)

(<http://archpedi.jamanetwork.com/article.aspx?articleid=518355>)

One study found that mental health professionals protect the confidentiality of older minor clients (16-18 years of age) to a greater extent than for younger minor clients (11-15 years of age).

“There are two factors that consistently mitigate decisions to breach confidentiality among mental health counselors in private practice and other employment settings. The first is age of the minor child, with greater autonomy to make individual decisions afforded older clients. The only exceptions were clear threats of violence with guns. While most authors agree that minors have similar rights to privacy as adults, the age of the minor seems to change counselors' prediction of how they would handle those rights.”

(<http://www.biomedsearch.com/article/Confidentiality-with-minors-mental-health/80553853.html>)

Although not specifically related to mental health care, a survey, of high school counselors, found that they were more willing to break confidentiality when risky behaviors were “more intense, more frequent and of longer duration” and that there was variance with regards to the counselors willingness to break confidentiality when suicidal ideation was present.

(<http://schoolcounselor.metapress.com/content/7873732816122842/>)

Finally, ethical studies have found that “paternalism” (i.e. – disclosing adolescent health conditions with parents) was justified only in cases where protecting the adolescent’s life was the central goal.

(<http://www.ncbi.nlm.nih.gov/pubmed/2606747>)

### Confidentiality and Mental Health Treatment for Medical Students

Surveys of depressed medical students have also found that lack of confidentiality is a barrier to seeking mental health treatment.

([http://journals.lww.com/academicmedicine/Abstract/2002/09000/Depressed\\_Medical\\_Students\\_Use\\_of\\_Mental\\_Health.24.aspx](http://journals.lww.com/academicmedicine/Abstract/2002/09000/Depressed_Medical_Students_Use_of_Mental_Health.24.aspx))

(<http://www.jgme.org/doi/abs/10.4300/JGME-D-09-00086.1>)

### Stigma and Mental Health Treatment

Another important policy topic related to the use of mental health services is perceived stigma attached with mental health illness, and the consequence for seeking mental health treatment can be, “...negative evaluations and rejection from others.”

(<https://wesfiles.wesleyan.edu/courses/PSYC-309-clwilkins/Week4/Sibicky.%20Dovidio.1986.pdf>)

The academic literature has found that stigma can be an important barrier to seeking mental health treatment.

(<https://selfstigma.psych.iastate.edu/sites/selfstigma.psych.iastate.edu/files/self%20stigma%20mediation.pdf>)

(<http://www.ncbi.nlm.nih.gov/pubmed/15491256>)

Loss of social status was also cited by 62% of employees in one national survey as a barrier to seeking treatment.

(<http://www.ibhi.net/employees-report-mixed-feelings-about-seeking-health-care-treatment/>)

One scientific study on the topic found that the perceived stigma associated with seeking mental health care among university students was inversely associated with seeing a need to seek such care (i.e. – students had higher perceived stigma if they felt they did not need to seek care while students had lower stigma associated with seeking care if they felt they did need it.); while amongst students with probable depressive disorders, there was no evidence of perceived stigma effecting use of mental health services.

(<http://ps.psychiatryonline.org/article.aspx?articleID=99261>)

Another study from Germany found the following:

“Contrary to expectations, anticipated discrimination from others was unrelated to help-seeking intentions, while personal discriminatory attitudes seem to hinder help-seeking.”

(<http://link.springer.com/article/10.1007/s00406-009-0870-y>)

And, a study from Australia found:

“Seeking help from a [general practitioner] for psychological problems was predicted by having a positive attitude towards seeking psychological help ... [c]ontrary to expectations, perceived stigma didn’t influence help seeking.”

(<http://link.springer.com/article/10.1007%2Fs00127-006-0089-4?LI=true>)